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AUTHOR Fahey, Charles J.; And Others
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ABSTRACT

The introduction to this Technical Committee Report describes the committee's procedures, provides an overview of long-term care, and enumerates assumptions and values identified by the committee as important factors in the formation of recommendations. Four major findings and seven key issues of the committee are also listed. Eight committee-adopted recommendations covering both broad and specific strategies to improve the delivery of health and social services to persons "at risk" are offered as a framework for the 1981 White House Conference on Aging delegates to debate how public policy can be made more responsive to the needs of this vulnerable group. The recommendations for the establishment of an organized system of long-term care are concerned with: (1) the focus of a long-term care system; (2) informal supports and family caregiving; (3) the community long-term care system; (4) mental health; (5) sponsorship; (6) quality and appropriateness of care assurances; (7) financing; and (8) human resources. A glossary of terms and an executive summary of this report are also included. (NRB)

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WHITE HOUSE CONFERENCE ON AGING, 1981

Social & Health Aspects of Long Term Care

Report and Executive Summary of the Technical Committee

MSGR Charles J. Fahey, S.J., Director
Center on Gerontology, Fordham University, NY
Chairman, Federal Council on Aging

Joseph E. Becker
John Beck
Homer W. Cunningham
William L. Gee
Ernesto Martinez
Joan Quinn
William Reichel
Janet S. Sainer
Malcolm O. Scamahorn
Jerry D. Smart
Herbert H. Shore
Gladys R. Voegtli
Ellen Winston

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the 1981
White House
Conference
on
Aging

Report of

Technical Committee

on

SOCIAL & HEALTH ASPECTS OF LONG TERM CARE

TCR-8

NOTE: The recommendations of this document are not recommendations of the 1981 White House Conference on Aging, or the Department of Health and Human Services. This document was prepared for the consideration of the Conference delegates. The delegates will develop their recommendations through the processes of their national meeting in late 1981.

TECHNICAL COMMITTEE MEMBERS

MSGR Charles J. Fahey, S.J., Director
Center on Gerontology, Fordham University, NY
Chairman, Federal Council on Aging

Joseph E. Becker
Nursing Home Administrator
Masonic Home, NJ

John Beck, MD, Director
Division of Geriatric Medicine
UCLA

Homer W. Cunningham, President & Chairman of the Board
Progressive Medical Groups, Inc.
VA
Chairman of the Board, Meals on Wheels, VA

William L. Gee, DDS, President
On-Lok Senior Health Services for Pacific/Asians, CA

Ernesto Martinez, Director of Senior Programs
East Harlem Council for Human Services, NY

Joan Quinn, MS, RN, Executive Director
TRIAGE Long-Term Care Project, CA

William Reichel, MD, President
American Geriatrics Society
Washington, DC

Janet S. Sainer, MS
Commissioner, NYC Department for the Aging, NY

Malcolm O. Scamahorn, MD
Chairman, Committee on Aged and Long-Term Care
American Medical Association, IL

Jerry D. Smart, President
American Association of Homes for the Aged, DC

Herbert H. Shore, Ed.D.
Executive Vice President
Dallas Home for Jewish Aged, TX

Gladys R. Voegtli, Chairman
Long-Term Planning Committee
State Advisory Council to the Wisconsin Bureau on Aging

Ellen Winston, Ph.D., Chairman
N.C. Governor's Advisory Council on Aging
President, National Council on Aging
Deputy Chairman, 1981 White House Conference on Aging

COMMITTEE STAFF, CONSULTANTS, EXPERTS

Charles Culhane
Consultant-Writer
Washington, DC

Burton Dunlop, Ph.D.
Abt Associates
Washington, DC

Elizabeth D. Flynn
White House Conference on Aging Staff

Douglas S. Hill
White House Conference on Aging Staff

I. INTRODUCTION

A. Committee Procedure

The White House Conference on Aging Long Term Care Technical Committee operated as a single unit to determine the outline and direction of the Committee's report, develop issues, and formulate policy recommendations.

The Committee met four times: in Washington, D.C.; in Reston, Va.; and in Dallas, Tx.; from July, 1980 through January, 1981. During the first meeting, members were asked to identify the most important long term care policy questions and rank controversial subject areas. Next, staff worked with the chairman to develop an outline based on approximately forty separate recommendations. These were grouped into nine topical areas for review by the members at the September meeting.

At the end of the second meeting these forty items were restructured and became the basis for development of a discussion paper of critical issues to frame the debate for public policies on the subject.

The staff developed eleven issues and recommendations in preparation for the December meeting. With minor modifications, these were accepted and became the basis for development of an Executive Summary to be incorporated into the National White House Conference on Aging Delegate Workbooks.

Two consultants, Dr. Burton Dunlop of Abt Associates, and Charles Culhane, an editorial consultant, both of Washington, D.C., were employed to refine the Executive Summary and develop a detailed paper explaining the recommendations. Sections of the Executive Summary and the detailed report were written by staff.

A first draft of the Executive Summary and the detailed report were prepared for the January meeting.

During February, staff and the consultant developed the final reports in consultation with the chairman and the

committee.

B. Overview

The most commonly held perception of long term care is one of institutional services. In fact, long term care involves not only institutional services, but a wide range of social as well as health services provided to people in a variety of settings.

The 1971 White House Conference on Aging expressed the need for an organized system of long term care. The 1981 White House Conference on Aging Long Term Care Technical Committee has focused on what continues to be a "non-system" of long term care, by recommending that public policymakers fashion and demand an organized and coordinated delivery system of long term care that fully recognizes both social and health needs. The person in need of long term care is one who, because of a social, physical, and/or mental condition, is unable to cope with the tasks of daily living without assistance for an extended period of time. It is the belief of the Committee that such a person should be the focus of a long term care system.

Nursing home expenditures during the twelve months ending in June, 1980, were 19.3 billion dollars.(1) Based on the most recent available data, non-institutional health and social services expenditures provided under the Older Americans Act and the Social Security Act were approximately 1.3 billion dollars. (*2)

Based on these striking facts, and on the widespread dissatisfaction with the current approach, the committee supports a coordinated strategy for long term care and support in which the institutional and non-institutional components are more appropriately balanced. There should be a continuum of social and health support services, both institutional and non-institutional, which would allow for home-based and/or community care, encouraging maximum functional independence.

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* Because data collection in long term care is neither ordered nor unified, truly equivalent comparative data are not available. This particular comparison is based on two sets of data:

1. Quarterly annual costs of social services under Title XX of the Social Security Act, October 1978-September, 1979.

2. Quarterly Financial Status Report, Title III-B, and III-C of the Older Americans Act, 9-30-80; 6-30-80; 3-31-80; 12-31-79.

Long term care financing has focused primarily on care provided in medical institutions. As a result, the system has been driven in that direction by policies that foster institutionalization. Few options are available to older persons who need social or medical services that will assist them to remain in their homes or other residential settings.

Demographic projections consistently show a major increase in the number of older persons in the United States in the next thirty years. As this population increases, so will the number of older adults who will require care and support. Presently, approximately eighty percent of the care and support available to older adults is provided by family members or other informal support systems. It is essential that any formal long term care system recognize and support the informal system currently at work. Further, such a system should help to facilitate the provision of a variety of formal and informal services to assist older people to achieve and maintain optimum well-being.

The Committee identified the following assumption and values which were important factors in the formulation of its recommendations. They do not constitute a definitive list, but rather highlight some of the more important background elements for consideration by White House Conference delegates.

1. Assumptions and Values

Assumptions

a. Most long term care is provided within the context of the family and other informal supports. In some instances, formal supports supplement and even make such care possible.

b. The demand for long term care will grow as more Americans continue to live to an advanced age.

c. Financial constraints will intensify:

(1) Other national priorities will compete with and restrain the growth of publicly financed health and social services;

(2) Inflation will probably persist in the health and social service fields.

d. Functional disability occurs at all ages but particularly among older Americans.

e. The nature of disability is such that functional changes are likely to occur. Programs must be flexible in order to be responsive to an individual's changing level of needs.

Values

a. Society should assure that humane, continuing care is provided to vulnerable individuals in their own homes where possible or in group settings when necessary.

b. Long term care services should be available to persons with functional limitations who need assistance.

c. Society should ensure that necessary services, both formal and informal, are available.

d. The system should provide services to people at home and in institutions.

e. Programs should be flexible in order to respond to individuals' changing needs.

f. Government should provide a variety of services that assist families and other mediating structures* with informal care giving.

g. The individual should be able to choose among service options.

h. Cultural, religious, and ethnic preferences should be respected in the provision of services.

i. Care that is provided should foster independence.

j. Government should assure that the rights and dignity of all persons, including those who are most vulnerable, and most in need of services, are preserved.

II. MAJOR FINDINGS AND KEY ISSUES

A. Findings

The major findings of the Committee are the following:

1. The focus of a long term care system is the person who has functional difficulties and is in need of assistance in the activities of daily living in order to assure continuing independence.

2. Public policy should provide the necessary mechanisms for the enhancement and supplementation of the individual, of the family, of other significant individuals, or mediating structures.

* See Glossary

3. Each community should have a publicly sanctioned long-term care system which provides for continuity of care, multiple entry points, and coordination of needed social and health services in homes and institutional settings through governmental, proprietary, and non-profit organizations.

4. A long term care Assessment/Case Management function should be available as a matter of entitlement to all persons 75 and older as well as those under 75 who are functionally disabled.

B. Issues

1. How should public policy provide for the enhancement of the care-giving capacity of family and friends as part of the informal system of long term care?

2. Should there be a local system of long term care and what should be its characteristics?

3. Should all functionally disabled persons be eligible for a case assessment and case management system as a matter of entitlement?

4. What can be done to assure a balance between institutional and non-institutional services? e.g. How should services in homes and institutions be provided in the least restrictive environment appropriate to an individual's functional capacity?

5. How can the current health care reimbursement system, particularly in relation to health care providers, be improved?

6. How should appropriate and quality care be assured?

7. Should the federal government study the feasibility of a social service insurance program for disabled persons?

III. RECOMMENDATIONS

Drawing on its review of current and future long term care policy issues, the Committee adopted eight recommendations covering broad and specific strategies to improve the delivery of health and social services to persons "at risk." These will serve as a framework for the 1981 White House Conference on Aging delegates and others to debate how public policy can be made more responsive to the needs of vulnerable people with problems which make it difficult to cope with daily living.

A. The Focus

The focus of a long term care system is the person who has functional disabilities and is in need of assistance in the activities of daily living in order to assure continuing independence.

Currently, the vast bulk of care received by functionally disabled persons -- i.e. those impaired socially, physically or mentally, and needing help in carrying out the normal activities of daily living such as personal hygiene, meal preparation, financial transactions, housekeeping, etc. -- is provided informally by household members, relatives, neighbors, and friends.

Formal long term care services, which include nursing home care and various services delivered to the person at home by paid professional nurses, homemaker-home health aides, and choreworkers, are obtained largely in piecemeal fashion from an assorted array of programs and provider agencies. For the most part, recipients of publicly funded formal services receive them only if they are beneficiaries of an entitlement program such as Medicare or Medicaid, the focus of which is to provide medical care to persons who otherwise could not pay for it. Formal services provided under other programs such as Title XX of the Social Security Act and Title III of the Older Americans Act are broader in the population that they will serve. These programs are very small in comparison to Medicaid, are funded at rather low levels and do not represent a comprehensive approach to providing long term care services.

Beginning with the inclusion of nursing homes under state licensing programs and under the Hill-Burton program in the early 1950's, publicly funded services for the care of the chronically disabled elderly population have been medically and institutionally oriented. This orientation remains today in the Medicare and Medicaid programs. Under these programs, medical models of care have been transferred to services provided in homes as well as in institutions.

Under Medicare, services normally provided to persons with chronic conditions are available only to the degree that they support a medical plan of care for acute symptoms of a specific, clearly diagnosed illness. Medicare thus represents the medical diagnosis model of care in almost pure form.

Under Medicaid, the dominant program providing long term care, an applicant must exhibit both a medical or health need and meet an income and resources means test in order to receive services. The major consideration under this program is financial need, as this program was established to assist poor people. Determination of medical need can be

judged, to some degree, if a person's income and assets fall below designated levels decided by each state. Those persons who fail to meet income and assets criteria either must go without Medicaid services or find some other means of purchasing them, at least until they have spent or gotten rid of these assets to the point at which they qualify for Medicaid benefits. In most states, services covered are restricted to medical or health-related care. Medicaid thus epitomizes a financially focused method for allocatiing long term care services among the functionally disabled population. (3)

Obviously, persons with chronic functional limitations have at least periodic medical care needs. They frequently have difficulty obtaining adequate housing. Income maintenance is another problem. These are important components of any strategy to provide care for a disabled population. But none is broad enough to deal with functionally disabled persons in a comprehensive fashion. Interest is increasing in a psycho-social approach which begins with the individual and builds a service plan shaped around a persons's total needs rather than one which requires the fitting of individuals into programs that provide a particular service for a particular sub-population.

The Committee's recommendation, then, envisions that the focus in the provision of long term care is the functionally impared individual with a chronic disease or condition who needs assistance in carrying out the normal activities associated with daily living. Most of these impairments are neither medically nor technologically complex and are continuous and/or recurring.

Although accurate measures of functional disability are still imperfect, the multi-dimensional approach is superior to a determination of need limited to medical diagnosis and financial status. To bring order to the current "non-system", long term care needs should be assessed periodically and addressed flexibly on the basis of an individual's complete functioning level at any point in time.

B. Informal Supports

Public policy should provide for the enhancement and supplementation of the capabilities of the individual, of the family, significant others, and other mediating structures. Informal supports given by family and family-like helpers provide much help to individuals with long term care needs. The General Accounting Office estimates that sixty to eighty percent of all chronic and functionally impaired persons with slight to severe disabilities are helped by families in significant ways.(4) These conclusions indicate that family care-giving activities provide a wide range of personal care

and social supports in homelike settings. Not surprisingly, the availability of effective family support is instrumental in keeping many older persons at home.

Since families and relatives provide much of the care needed by older persons, it is critical for public policy makers, as a primary goal, to provide ways to sustain and enhance the capacity of families and family-like helpers. At a second level, public support is needed to expand care provided by neighbors, volunteers, churches, and voluntary organizations. These informal sources of help are particularly valuable in addressing the social and emotional needs of non-institutionalized widowed persons and those who never married, who comprise thirty percent of the older population. When these levels of aid are inadequate or unavailable, formal health and social services for which providers are compensated, become the principal sources of support.

An important consideration with respect to the best way to sustain or increase family supports to impaired elderly relatives is the use of public dollars either to provide direct health and social services or to offer regular cash supplements, tax credits, and other financial incentives.

Demographic trends indicate that in the future there will be a significantly higher proportion of older people in the population as well as rapid changes in family care-giving patterns. More families are likely to confront stressful conditions that can erode their ability to provide support. In the 1980's, very old people will continue to be the fastest growing population group. Persons aged 85 or more will triple their numbers by the year 2035. (5) Moreover, the capacity of children to provide for parents of advanced age will be diminished by their own aging problems.

By the year 1995, the number of widowed, never married, and single divorced elderly is expected to exceed elderly married persons, (6) critically reducing the level of support currently provided by spouses and shifting more responsibility to other family members.

Women traditionally have been the principal care-givers and, in most households, the primary sources of personal care and emotional support to aged family members. Their ability to continue in this mode is complicated by growing work force participation. This trend is projected to continue through 2000 and especially affects women 45-54, the principal care-giving ages.

Trends in contemporary family structures in which divorce and remarriage are common may affect the capacity and commitment of particular family members to provide for the care of relatives.

1. Family Care-Giving Functions

The preferred care-giving patterns of families and their impaired relatives are weighted toward direct service and social supports rather than financial assistance. Transportation, friendly visiting, counseling, homemaker-home health aide, and chore services are the principle support activities.

Families are willing to endure considerable personal and economic sacrifice for the care of older relatives. Studies show greatly impaired relatives rely more heavily on spouses or children for support than formal care available through nursing homes or community services. (7)

Changes in these care-giving patterns are triggered by emergencies or crisis points that significantly diminish care-giving capacity. These are related to rapid deterioration of the disabled, loss of primary care-givers, and reduced capacity of helping family members, because of fatigue and income loss.

When family care-giving is imperiled, there is a greater tendency to turn to neighborhood, volunteer, church, and non-profit community groups for advice and assistance. Formal supports are introudced to resolve technical, specific and continuing problems. Nursing home and other institutional placements are chosen only when families exhaust other sources of help.

2. Strategies to Enhance Family Care-Giving

There are three strategies to strengthen the willingness of family or family-like helpers to care for the chronically disabled and functionally impaired. Each must be considered within a framework that assures appropriate community services and maintains the integrity of informal helping networks. They are: enhancement of informal supports, formal service supports, and financial assistance to families.

Informal Supports: Informal or natural supports are offered free to families with dependents "at risk" and include individuals and providers linked mostly to privately funded, non-profit, community-based organizations. They include volunteers, churches, some voluntary agencies, and neighborhood groups. They supplement the personal care and basic living service activities provided by families and family-like helpers.

Volunteers, collaborating with skilled professionals, are in a unique position to humanize and improve the long term care system. Estimates by the National Council on the Aging indicate that volunteers give a minimum of 25 million

hours a year to persons 65 and older. (8) Studies show that older volunteers, with proper training, and under professional supervision, are particularly adept at providing direct social care to frail, impaired persons and to families with diminished care-giving capacity. They provide friendly visiting, help with meals, telephone reassurance, grooming, assist in prescribed physical therapy regimes, and make sure that clients have access to community services to which they are entitled.

The Committee believes that this resource could be enhanced through tax credits to volunteers or non-profit agencies that provide long term care volunteer services. Further, expansion of ACTION's Older Americans volunteer programs, specifically the Senior Companion Program and the Retired Senior Volunteer Program, is another option. Each of these programs is heavily engaged in direct social support activities to older persons with mobility limitations.

Philanthropic organizations such as the United Way of America Agencies and the American Red Cross Chapters augment informal supports to neighborhood groups and families by identifying needs, providing direct emergency and maintenance services, and monitoring private and public long term care support programs for accountability and effectiveness. Unfortunately, contributions to these organizations have barely kept pace with inflation.

This has resulted in great difficulty meeting basic needs, and even greater difficulty in meeting the increasing demand for expanded service. The Committee believes that care provided through private initiatives outside the publicly sanctioned system, is essential. Public policy should strengthen these efforts rather than destroy or ignore them.

Churches and synagogues also are expanding efforts on behalf of persons at risk and their families. The National Interfaith Coalition on Aging, representing a constituency of 262, 766 congregations, has pledged to vitalize and develop the role of churches and synagogues in improving the quality of life for the aging. (9) Each year more congregations are providing meals for older people, senior day care facilities, and actively supporting congregate interfaith housing projects in their communities.

<u>Assistance may take the form of financial help, such as income supplements and/or tax incentives, and social supports, such as day care, homemaker-home health aide services, and respite services.</u>

Increases in income tax credits or tax deductions are among the financial incentives which should be explored. They include home improvement loans to construct additions to homes for elderly relatives in need of care, or property tax deductions and across-the-board increases in basic income tax credits for older dependents.

Another option is direct financial grants to families either in the form of long term care vouchers or cash supplements. Vouchers enable individuals or relatives, acting on behalf of friends or families with long term care situations, to purchase care on the open market rather than through third party reimbursement mechanisms. Recipients would receive vouchers containing fixed dollar amounts for services which may be purchased in prescribed time periods from certified agencies, public or private.

This gives a measure of autonomy to families in their choice of providers and the types of services they can choose. This free market approach should enhance the variety and quality of services offered by providers at competitive prices. One disadvantage is that over-utilization can result when persons at risk use the system and disregard care provided informally or formally at adequate levels from other sources.

A third possibility is direct long term care cash grants to families. Unfortunately, they do not necessarily assure that long term care funds will be used for the care of needy relatives. The redeeming features are flexibility and autonomy in the purchase of services from providers. It would appear that co-payments, combined with controls for use and eligibility are necessary to make this a practical strategy.

For persons "at risk" who live with relatives, day and respite care services on a temporary or permanent basis, can provide opportunities for family members to retain full or part time jobs, take vacations, and generally ease the stress of caring for older relatives. Some ways of encouraging these services are broader use of senior day care centers and tax incentives to operators of day hospitals and nursing homes.

Direct service supports are particularly attractive to families because benefits are geared to specific long term care conditions. These include: professional in-home medical care, health and social service assistance, homemaker-home health aides, chore services, legal counseling, and other means.

C. The System

Each community should have a publicly sanctioned long term care system which provides for:

a. Person-focused case managment with the capacity to assess need, determine eligibility, provide linkages for those in need of formal services and assist the person in his or her informal support system.

b. Continuity of care, which assists informal supports, provides multiple entry points, makes available both in-home and group services, offers both social and health services, provides psycho-social and health assessments and reassessments, and makes resources available to fill emergency gaps in service.

1. Scope of the Problem

Functionally disabled individuals, or agents acting in their behalf, must now choose from a potentially confusing mixture of programs, funding streams, and sub-systems in order to receive formal long term care services. These include: Medicare, Medicaid and Title XX under the Social Security Act and Title III under the Older Americans Act. (10) Other sources of formal care are income support programs such as Supplemental Security Income (SSI), Old Age Survivors and Disability Insurance (OASDI), food stamps, one of several housing subsidy programs funded under the Deparment of Housing and Urban Development (HUD), (11) federal and state-sponsored mental health programs and for veterans, one of several Veterans Administration programs.

Because each of these programs, or funding streams, is funded separately by the federal government, each involves a separate sponsoring agency or agencies at the state and local level. As a consequence, eligibility criteria vary enormously from program to program, creating a ti[illegible] bewildering situation for the consumer. (12) Mo[illegible]over, because the federal government assigns varying degrees of discretionary authority to states and localities in operating these programs (depending on whether the funding mechanism is a categorical grant, or some degree of special or general revenue sharing), benefits and eligibility criteria under the same program vary dramatically across states and across localities within the same state. (13)

One of the major dilemmas facing long term care policy makers is whether such care should be provided through the health care system or through the social service system, or both. Long term care clearly straddles both of these arenas. Since adoption of medical assistance programs containing provisions covering nursing home care in the early 1950's and culminating with the Medicaid program in 1965, the bulk of funding for formal long term care has come under the medical/health agencies. It has focused on institutional care and operates largely in terms of physical structure and accommodation (or on the care level of the wing or bed to which a resident is assigned) rather than in terms of quality or appropriateness of the care the resident is receiving.

Under the present structure the individual must be responsive to the system rather than the reverse.

The imposition of the acute care quality standards used in hospitals upon nursing homes has meant the same kind of regimentation of life associated with hospital stays. Since the expected hospital stay is short, setting aside the normal amenities of residential living is tolerable. The effect of this imposition of standards is mirrored in nursing home care-giving in which many patients have experienced unnecessary regimentation. Others have chosen to avoid needed residential support services because they do not want to live in a restricted nursing home environment.

Quality assurance generally has been the responsibility of health departments that rarely are the relevant funding agents. Recently, quality assurance and appropriateness determination for skilled nursing homes, and for intermediate care facilities in some states, have become the responsibility of Professional Standards Review Organizations (PSRO's). These groups of physicians, often local medical societies, also are responsibile for data collection, but overall data collection for planning purposes rests with local Health Systems Agencies which are established apart from any program agencies. Thus, the need for improved coordination of this fragmented arrangement of providing long term care services is obvious. The extent to which it is a problem, the degree to which its disadvantages outweigh benefits and the number of persons needing assistance in negotiating an acceptable care package are not known. (14)

2. Other Problems

Even an optimal degree of coordination, however, would leave largely untouched other problems associated with long term care delivery. Service gaps still would exist because all of these programs and funding sources are geared largely to the provision of medical care or income maintenance. Psycho-social needs remain largely unmet. Too few mechanisms currently exist for assessing these kinds of needs as part of a site individual needs assessment process. Moreover, once health and social care needs or income needs are assessed, the person involved tends to get locked into a single service strategy regardless of significant changes that may take place in his or her condition. Periodic reassessment is rare and the services to meet changed needs may not be available even when significant changes are identified. Moreover, if the care need identified does not fit into funded program regimens in approved settings, that need tends not to be addressed.

Available programs and funding sources are largely inflexible in the kind of service they will cover and none is specifically a long term care program. A recipient of any of these services receives the service because he or she

happens to be part of a sub-population toward which that program is aimed. The way in which the functionally impaired individual links up to any of these services is haphazard. There is no formal linking mechanism at the local level.

3. Community System

In order to coordinate the multiple health and social needs of functionally disabled persons, the Committee recommends that communities have publicly sanctioned long term care systems. The rationale for a locally based system stems from a variety of Health and Human Services (HHS) and private programs that indicate that communities are the logical points at which responsibility should be fixed if long term care programs and services are to be responsive to local conditions.

The long term care system should have the capacity to arrange for whatever informal and formal services the client needs and desires, whether provided in the home, in a group living arrangement, e.g. congregate housing, or in an institution. Need would be determined on the basis of a comprehensive assessment not only of mental and physical health and functional capacity, but also living arrangements economic resources, availability of care-givers, cultural preferences and other psycho-social factors.

Emphasis should be on an on-going, person-focused case management with multiple entry points to a variety of community services and with follow through whether individuals are screened in or out of programs. Plans of care for persons at risk should be developed without bias for a particular service and in a manner that augments the independence of clients and their informal supports.

Eligibility for service would not depend upon the client's economic status, medical diagnosis, or residence in a particular building that meets standards for participation in some federal program. The agency should have the authority to arrange for those services that least limit the person's normal functioning and consistent with the person's actual level of functioning in carrying out the activities of daily living, i.e., eating, dressing, toileting, bathing, cooking, cleaning, shopping, making financial transactions, etc. Assessment of composite needs should be continuous and service arrangements should be altered to reflect any significant changes in care need. The current bewildering and time-consuming practice by which the potential client must be assessed separately for eligibility by each of the agencies and programs through which he or she seeks services should be eliminated through effective case management.

Monitoring the condition of clients for continuing appropriateness of services is an important function of the system. Over time, a homebound person may need a different mix of services. Institutionalized clients should be reviewed periodically and returned to community life if desired and warranted. The growth of institutional dependence may precipitate the need for indefinite institutionalization, and should be discouraged.

The service agency should have funds to cover the needs of clients in emergencies and to purchase services not covered by existing programs for which the person in need is eligible. This will add to the range of services on which the system can draw, making it more effective.

4. Sufficient Data Capacity to Facilitate Planning and Measure Outcomes

The agency should systematically collect data on clients, on community resources, and on service utilization patterns in order to plan for future service needs, thereby increasing options to meet clients' needs. For example, cumulative data can determine whether institutionalization occurs because the capacity for formal community-based care is limited, service gaps exist, or lack of family support promotes institutionalization.

5. Appropriate Control Over Reimbursement to Providers

Some control over reimbursement to providers is necessary for monitoring purposes. However, new reimbursement procedures need to be developed that offer incentives for achieving high standards in the provision of care, and thus help to encourage the delivery of good quality care.

SUMMARY

This system, as described, bears some resemblance to current proposed legislation contained in the Conable Bill (H. R. 58), the Pepper-Waxman Bill (H. R. 6194), and the Title XXI proposal. It also resembles closely the incremental single agency option sketched by Callahan, (15) and the gate-keeping mechanism outlined by the General Accounting Office (GAO).(16) A major difference in the GAO model, however, is that the local long term care entity would act as a single funding source for all services rather than a source of gap-filling funds only.

The community long term care system envisioned by the Committee appears to avoid the potential pitfall noted by Callahan of agency absorption in direct services resulting in short shrift to the desired activities of assessment, case management, eligibility determination and data collection.

D. Mental Health

Mental Health should be an integral part of a comprehensive long term care health and social service delivery system. Funding patterns should reflect such integration.

The incidence, and prevalence of emotional and mental health problems of older persons have been seriously under-estimated. Mental illness is more prevalent in the elderly than in younger adults. An estimated 15 to 25 percent of older persons have significant mental health problems, and the percentage increases for the group aged 75 and older. (17) The chronic health and financial problems of older people clearly contribute to increasing stress.

There is also a continuing trend to transfer older residents out of costly mental hospitals into less expensive boarding homes. Very often these homes lack adequate psychiatric care resources since there are few mental health professionals trained to deal with the specialized mental health needs of the elderly. There is also reluctance on the part of people trained in mental health to treat the service needs of older people in the home, in long term care facilities, and in other residences. The traditional office visit is seldom appropriate for persons with limited mobility.

There are many other problems relating to the current approach of mainstreaming patients from state hospitals into community care. Many mental disorders respond to treatment and are reversible. Since nursing homes are the basic surrogate mental health facilities in the community, an older person whose behavior is inappropriate is often viewed as senile and put on a drug regime without any effort to determine or treat the problem. Drug control regimes often exacerbate physical problems and contribute to new medical concerns.

For the non-institutionalized elderly there has been a continued reluctance to admit a need for, and use mental health services. It has been found that only one percent of the people who come to community health centers are 65 and over. The present older segment of the population perceives a stigma attached to a need for psychiatric help. Studies indicate a belief that an individual who does not have a diagnosed long term care illness should be able to resolve problems related to stressful life situations. Additional problems involve high costs, restrictions on Medicare and Medicaid coverage, limited availability, accessibility and appropriateness of programs that focus on the needs of the older person "at risk."

Traditionally, mental health systems and health service systems have operated separately. There has been minimal effort to promote total health, both mental and physical. Social service delivery has therefore been fragmented in an effort to serve what are identified as separate needs, but in essence should be part of a comprehensive approach to long term care. (18)

The Committee further believes appropriations and funding should provide for:

1. Availability and accessibility of mental health care for older persons on a comparable basis with coverage for physical health care services. This implies redressing current inequities in third party programs paying for comprehensive mental and physical health and service delivery in long term care.

2. Education and training of providers for multidisciplinary teams for effective service in long term care.

3. A designated focal point at the state level to ensure that there will be assessments, coordination and planning of statewide health, mental health, and social services. Financial and technical assistance should be provided to the states for planning and development.

Lack of coordination of long term care health and social services is a detriment to the mental health of older people and their ability to minimize dependence and to enhance well being.

E. Sponsorship

Public policy should recognize pluralism in sponsorship. Private investment, governmental, and philanthropic, non-profit agency efforts are all necessary in the provision of long term care.

There has been a clear tendency in the health care field and in governmental health policies to equate provision of services under non-profit sponsorship with good quality and services provided under proprietary auspices with poor quality. Since funding for long term care has come largely from health dollars, it has shared in this perception. For example, Hill-Burton funds were made available only to non-profit nursing homes' sponsors.

Presently, only home health agencies under non-profit auspices can participate in the Medicare program without licensing by state health departments. As a result of this bias in the Medicare program, most home health care providers are non-proprietary although a very significant portion of home health service is delivered by proprietary enterprises.

This distribution by sponsorship is just the reverse for the nursing home field, the principal supplier of formal long term care. The following table shows the national distribution by percentages of nursing home facilities, beds, and residents, as of 1977.

Nursing Homes	Facilities	Beds	Residents
Proprietary (for profit)	76.8%	69.3%	68.2%
Voluntary (non-profit)	17.7%	21.1%	21.6%
Governmental (public)	5.5%	9.6%	10.2%
	100.0%	100.0%	100.0%

Source of data: National Center for Health Statistics, 1977
National Nursing Home Survey

Thus, the pervasive bias does not at all square with the realities of long term care provision in this country as a whole. This discrepancy seems unlikely to diminish in the future unless the bias is eliminated. Massive capital investment would be necessary for the government to replace proprietary nursing homes with non-proprietary ones.

The task would be far easier in the non-institutional service arena since non-profit suppliers are dominant there. Yet it would be difficult to justify and insist upon non-profit sponsorship in home-based or community-based care provision while allowing proprietary sponsorship of nursing home care. Moreover, a freedom issue is involved here: Why shouldn't a consumer or a local long term care agency have the option of choosing a proprietary service provider if they want?

In conclusion, the Committee recognizes the validity of a pluralistic approach in which a variety of proprietary and non-profit providers and voluntary and philanthropic agencies provide long term care service delivery. New configurations and alliances will take place in the event the market shifts from institutional to non-institutional services. The particular type of services will depend upon the availability of public funds to meet individual client requirements and the population of functionally disabled persons in community service areas.

Medicaid reimbursement should cover the actual cost of necessary incurred services.

Medicaid reimbursement rates for both nursing home care and home health care in most states fail to meet the true cost of care provision, according to most expert testimony. Since

Medicaid pays the costs of half or more of the nursing home population in the nation, this situation provides at least one reasonable explanation for the downturn in the growth of the bed supply since the mid-seventies. It may also help to explain the interest of home health care providers in Medicare certification and in serving Medicare clients, since Medicare rates are almost always higher than Medicaid rates.

As a result, the experts claim, private pay residents are often charged higher fees in order to compensate providers for their losses in providing care to Medicaid recipients. In effect, it is claimed, private pay residents and other payors subsidize the care of Medicaid residents. Besides the questionable equity of this situation, one common consequence is that private pay patients more quickly deplete their assets to the point that they must become Medicaid recipients as well.

Moreover, it is a well-documented claim that providers tend to discriminate against Medicaid applicants in favor of private pay applicants. As a result, of course, it becomes more difficult to place Medicaid recipients; and in a significant number of instances, they remain waiting in acute care hospitals where the daily cost of care to the Medicaid programs is much higher than it would be if the patient were in a nursing home. To some degree, though probably to a lesser extent, this situation may apply to Medicaid recipients who could be cared for at home as well.

Finally, it seems reasonable to argue that quality care would be substantially higher in nursing homes -- especially in those facilities housing all, or almost all Medicaid recipients -- if Medicaid reimbursement rates kept pace with the true costs of care provision. Studies indicate that adequate payment helps to ensure adequate care.

Reimbursement policy should allow for a reasonable return on equity.

Since the fundamental objective of private enterprise is a reasonable return on investment, and since society depends heavily on private providers to supply long term care, especially nursing home care, it seems only reasonable that reimbursement policy under publicly funded long term care programs should provide for this cost factor as well as for the costs of care provision itself. Presently, the Medicaid programs of thirty-three of the fifty states make some provision for return on equity to nursing home operators. However, the lack, or inadequacy, of such provision may well contribute to a shortage of service for patients who been have declared eligible for Medicaid.

F. Quality and Appropriateness Assurance

There is a need to define as well as refine techniques for guaranteeing quality and appropriateness of care.

Quality and appropriateness assurance should assume the basic integrity of providers. Sanctions should be applied promptly and fairly when abuse occurs.

Community presence and involvement, such as volunteers, friends, and neighbors, are important elements in helping to assure quality care and should be encouraged.

Quality assurance is a broad term encompassing a wide range of activities designed to ensure that professionally accepted standards of care are met. "Quality assurance generally includes both the measurement of the quality of care provided (quality assessment) and efforts to improve it." (19)

Inextricably tied to quality assurance is appropriateness of care. Both are complex entities and therefore difficult to measure, particularly in a long term care setting. They involve the measurement not only of health care given, but also the measurement of psycho-social and functional conditions as well. This becomes very difficult in a setting in which the health, psycho-social well-being, and functional ability of many individuals are destined to remain static, or indeed to decline.

Under the auspices of the Health Care Financing Administration, fifty-four Professional Standards Review Organizations (P.S.R.O.'s) have undertaken demonstration projects for long term care quality and appropriateness review.

One demonstration project is a collaborative effort that involves the Colorado Foundation for Medical Care (the Colorado PSRO), the Colorado Department of Social Services (the Colorado Medicaid agency) and several other state agencies. The program is fully operational but is still evolving in an effort to forge appropriate and workable responses to long term care issues and concerns in Colorado.

The intent is to provide a mechanism for addressing problems and concerns relating to the institutional care of recipients under Titles XVIII and XIX of the Social Security Act, as well as any other relevant Titles, if authorized. One basic goal is to address the problem of maintaining and, where possible, improving the quality of care and services these patients receive. The goal includes an effort to assure that institutional placement is medically necessary and appropriate to the needs and conditions of the patient and that reimbursable utilization of institutional placement is appropriate and justifiable.

Some broad objectives of the program are to review the necessity for initial long term care institutional placement, assess the possibility of alternative modes of care, establish the level-of-care for federal recipients in long term care institutions, and assign an initial review date for continued stay.

Colorado also is involved in a study examining and comparing the cost and quality of home health care and institutional care. This particular study will address the continued development and testing of measures designed to assess quality of care provided in nursing homes. The study will develop similar measures for home health quality assurance review. Finally, the study will evaluate the cost-effectiveness of institutional and in-home long term care, both hospital-based and free standing, in order to help provide a basis for appropriateness of care decision making. This study is scheduled for completion in December, 1984.

The Committee believes that both Colorado projects, as well as a number of other projects, will contribute to improvements and refinements in the techniques needed to measure and ensure quality and appropriate care, both in and out of institutions.

Presently, one of the difficulties with long term care quality assurance is that its foundations often lie in what has been done in an acute care setting. Long term care quality assurance is more complex in that the time frame is much different than that of an acute hospital stay, and the psycho-social and functional conditions of the individual in long term care are as important as the health needs of that person. The fact is that the person who needs long term care is different physically, mentally, and socially, from someone who needs acute care services.

Along with studies, such as the Colorado projects, the Committee believes that community involvement in long term care settings also can help to ensure quality of care and appropriate placement. This approach has had a great deal of success through the Ombudsmen Program under the direction of the Administration on Aging (AoA). In this program, volunteers inform themselves of the conditions in which nursing home residents live, receive complaints, and work to resolve them. This approach can be effective in communities through volunteer efforts by church groups, neighborhood associations, and individual visiting. The simple presence of volunteers in both in-home and institutional settings can be very useful in maintaining high quality services.

G. Financing

Medicare, Medicaid, Title XX, and programs authorized by the Older Americans Act, as well as other major social service programs which address the various aspects of long term care needs should be maintained and strengthened.

The Committee recognizes the shortcomings in the current financing of long term care. Three problems are barriers to reform:

> (1) Restrictiveness in service coverage, mainly limited coverage of non-institutional services under existing funding sources. (2) Inefficiencies created by the presence of multiple funding streams with divergent requirements. (3) Inadequate funding to provide services for all who need them or to cover the full cost of delivering care of acceptable quality.

In the absence of a comprehensive federal long term care policy to resolve these issues and the concomitant scarcity of new health and social service dollars, the Committee recommends maintaining and strengthening the existing service programs in-home and community services, and addressing a few of the problems related to restricted access and quality control will provide strong foundations for a system that can be integrated into a cohesive structure in the future.

In recent years, policy makers have made a number of changes in Medicare, Medicaid, Title XX, the Older Americans Act, and other social service programs. They generally fall into the category of promoting access to services, improving the efficiency of the service delivery system, and enhancing the quality of existing services.

1. Current Demonstrations

Within the past five years a number of Health and Human Services (HHS) demonstration programs have been funded, testing a variety of major long term care problem areas. While the data are still incomplete, these efforts have shown the need for a gate-keeping mechanism, multidimensional needs assessment, a coordinating mechanism, a simple funding source, and controls over utilization and costs.

A central thrust has been to test the case management approach which addresses most directly, the problem of inefficiencies, and indirectly, the problem of escalating costs. These demonstrations were made possible through the approval of Medicare (222) waivers and Medicaid (1115) waivers. The most notable of these are Triage in Connecticut; Project Access in Monroe County, New York· Community Care Organization in Wisconsin; On-Lok

in San Francisco, California; the Georgia Alternatives Health Services Project in Atlanta, Georgia; and the New York State Long Term Care Home Health Care Program.

In addition to these demonstrations and others funded by HCFA and the U.S. Public Health Service, a major new channeling demonstration initiative has been launched by HCFA, AoA, and the Office of the Secretary of Health and Human Services for Planning and Evaluation, in 21 sites throughout the country. The goals are to discover how to improve the coordination of health and social services at the point of client intake and determine at the community level procedures to channel all available resources most effectively to the various recipients of care and services.

The Administration on Aging has undertaken a variety of independent long term care initiatives. Among them are assistance to state and local agencies in their efforts to develop a more comprehensive and effective continuum of care for the vulnerable elderly and to expand research and model project funds to improve accessibility to more appropriate and higher quality long term care.

Title XX of the Social Security Act is a major federal program for financing social service to vulnerable populations. Among services which need more resources are day care and foster care for adults, homemaker-home health aide and chore services, protective services for adults, and group activity centers for the aging.

The National Institute of Mental Health has developed a community support program in 19 states to improve services and supports for chronically disabled adults who do not require 24-hour treatment. They could serve as a national model to encourage states to integrate deinstitutionalized mental patients into community life.

The Administration on Aging, HCFA and a long term care task force organized by HHS, Office of the Undersecretary, have sponsored a number of white papers designed to explore a variety of new options for the financing and reform of current long term programs.

On the basis of these conceptual pieces, as well as other materials, the Office of Policy Analysis in HCFA has completed an overview of long term care policy with an emphasis on expanding non-institutional care. This paper discusses five more or less generic methods of federally financing this expansion that HCFA has chosen to analyze for potential policy implementation. Among these options is the incremental modification of the Medicaid program. Steps considered for altering Medicaid include capping federal medicaid expenditures for nursing home care, providing a higher federal share to states under Medicaid

for the costs of non-institutional services, raising the Title XX ceiling, and requiring some degree of family support or supplementation of the costs of providing long term care services to impaired relatives. These financing steps would operate in tandem with modifications in eligibility criteria, program benefits, and administrative procedures. (20)

Efforts to strengthen the current "system" also have generated the formulation of three bills that have been introduced but not enacted, in the last Congress to change the way long term care is financed. The Medicare Long Term Care Act of 1979 (H. R. 58, the Conable Bill) would authorize federal funding through a new Part D of Medicare for a number of community-based services as well as institutional care. The funding conduit would consist of federal grants to the states.

H. R. 6194, the Medicaid Community Care Act of 1980, (the Pepper-Waxman Bill) relies on an increase in federal financial participation under Medicaid, up to 90 percent for states expanding community care funding and assessments for at risk Medicaid eligibles. The Comprehensive Community-Based Non-Institutional Long Term Care Services for the Elderly and Disabled proposal, popularly known as Title XXI and promoted by Senator Packwood, is based on the Medicare model of federal third-party reimbursement with a co-payment requirement.

The basic functions of the long term care system, i.e., client assessment, eligibility determination, and case management, should be made available, as a matter of entitlement, to all persons over 75 as well as those under 75 who are functionally disabled.

Entitlement means that all persons 75 years of age and older and younger persons determined to have functional disabilities would have a legal right to receive a comprehensive assessment of their health and psycho-social needs and access to appropriate case management. This would provide a single entry point for referral to a range of formal and informal community long term care services in keeping with a person's ability to participate in the activities of daily living.

The Committee believes persons 75 and older should have a presumptive right to person-focused case management because a significant number of surveys and studies have shown that on the average, people at this age tend to be more functionally impaired or disabled than those under 75. Perhaps the most notable recent study, indicating a rough order of the magnitude of difference between those above and below age 75, is the GAO study of the Well-Being of the Elderly in Cleveland, Ohio. (21)

Implicit in this concept is the Committee's belief that national attention should focus on this group of older adults who have extensive health, social, economic, and environmental problems which threaten their ability to maintain their maximum level of independence without direct personal assistance on a continuing basis.

For this age group in particular, public long term care policies have attempted to screen people out rather than into services. Development of a comprehensive community-based long term care system, with an assessment/case management function as a core activity, will help to ameliorate the imposition of a means test as a condition for receiving long term care and the bias toward an institutionally oriented system which does not promote care for older people whose interests may best be served by remaining at home.

A case could probably be made for the argument that the threshold age is slightly higher than 75 or, at least, that it is moving upward. Should such a trend prove real and continue in future decades, the threshold age might need to be adjusted periodically, though it seems highly unlikely that it would require adjustment more than once or twice each generation. It is important to note, however, that at least one analysis of national health survey data suggests that decreases in activity level, on the average, are continuous by age throughout the life span and that no abrupt point of demarcation can be pegged at a specific age.

The Committee also is aware that a high percentage of functionally impaired persons with multiple activity limitations requiring some continuing assistance, are under age 75. These individuals should have access to services through the same system, provided that procedures are developed that certify the existence of specific chronic disabilities in conjuction with standards of participation in the program.

Federal funds should be available to the community for individual services in an emergency situation that fill gaps identified through the client assessment and case management process.

The Committee supports the development of a discretionary fund to be used by a local long term care authority to assist clients who need temporary or emergency services. It would be used in conjunction with client assessment/case management and apply during the initial assessment as well as the reassessment of need process. Money would also be available to designated community service agencies to help provide gap filling services. Local long term care authorities would have the option of using the funds at their discretion within these limits. This fund would not be used on an on-going basis to fill gaps in areas where services do not currently exist.

An immediate study should be made of the feasibility of a funded social insurance program for long term care.

The program would create as a matter of entitlement, coverage of long term care for the chronically disabled without a means test. The principal objective would be to increase the availability of long term care resources at the local level.

Services would be provided in a variety of locations and include nursing homes, personal care homes, congregate housing, and private homes. Possible service benefits include: nursing home services, home health, homemaker-home health aide and chore services, foster care, nutritional services, and physical therapy. No acute care services would be offered.

The program would be financed mainly by the federal government on a pay-as-you-go basis. Payments would go to a separate long term care trust fund. Possible sources of payment to the fund could include a combination of a mandatory payroll tax, general revenues, and an insurance premium. Special allowance would be made for poor people. Depending on design options, this funding could operate either separately or as an adjunct to national health insurance.

Among the study issues are: How would the program be linked to existing health care systems? At what age should individuals pay into the trust fund? What would the demand for benefits be? How would the program affect long term care services provided informally? What assessment techniques should be utilized? What would the program cost?

Since the risk of an extended period of functional disability in the latter years is common to virtually all members of society and since the provision of services to compensate for chronic and functional disabilities tends to be financially catastrophic, this approach deserves serious study.

The current level of living of the spouse of a person in need of long term care should not be lowered by requirements that force the non-institutionalized person to contribute excessive amounts of money to pay for the costs of care for his or her disabled spouse.

The thirty-five states that follow Supplemental Security Income (SSI) eligibility for medicaid benefits hold the spouse responsible for contributing to the costs of care only during the first month of a nursing home stay. Most of the remaining states however, practice to some degree "deeming" of the non-institutionalized spouse's income. This process makes the spouses's income available in some portion for payment toward the cost of nursing home care.

Numerous claims have been made by practitioners, at least in those states with heavy contribution requirements, that the non-institutionalized spouse is rather quickly improverished by this requirement and often cannot continue to provide for his or her own maintenance in the community. For example, a couple that received a monthly SSI payment of $357 while living together is reduced to payments of $25 for the institutionalized spouse and $234 for the spouse still at home. Rules for couples receiving Medicaid, but not SSI, require a similar reduction in income.

It is found that the only option, in too many instances, is that both spouses have to enter a nursing home even though one may be capable of independent living.

A federal housing strategy should be developed which provides social supports to maintain an individual independently while helping to avoid premature or unnecessary institutionalization.

Virtually everyone knowledgeable in long term care recognizes that lack of congregate housing arrangements comprises a serious gap in the provision and availability of long term care services. A recent GAO survey has made this explicit. (22)

Other studies point to the number of older people in public housing who lack basic living services and have relocation to nursing homes as their only viable option.

As a result of this widespread concern, a number of demonstration efforts to provide congregate housing have been launched by the Department of Housing and Urban Development (HUD), Department of Health and Human Services and even the Department of Agriculture. At least two of these efforts are joint ventures of two or more of these Cabinet-level departments. Their efforts are too new to have produced any measurable results in terms of reducing unnecessary institutionalization in nursing homes.

Persons who qualify for skilled or intermediate in-patient care under Medicaid should be eligible for equivalent in-home services so long as the in-home expenditure does not exceed comparable in-patient cost. State Medicaid plans should reflect such a policy.

Many disabled elderly need a variety of services but do not require institutionalization. These individuals can live in a place they choose, provided they have the support of community-based services such as home health care, personal care, homemaker-home health aide and chore services, adult day care, and congregate or home-delivered meals.

Home health covers an array of services such as skilled nursing, can be provided in the home. Both Medicare and Medicaid currently fund some home health care services under certain somewhat restricted conditions. In FY 1978, two percent of Medicare expenditures, and one percent of Medicaid expenditures covered home health benefits. (23)

Some of the problems surrounding the delivery of home health care are inadequate data on the cost effectiveness of such care, how to ensure quality, and how best to provide delivery.

Among the barriers that exit to home health care delivery are:

1. Lack of a coherent federal policy.
2. Lack of coordination of services.
3. Lack of a continuum of health, social and support services.

A number of federally-sponsored projects are working with home health care delivery and attempting to overcome the barriers that currently exist. Most have successfully demonstrated not only the cost-effectiveness of alternatives to institutionalization, but also high quality care and the efficient use of community resources. However, the data at this point are inconclusive and incomplete and there remains a need for further data collection and analysis.

A recent study (June 1980) in Minnesota, that compared home health care and nursing home care expenditures, concluded that the cost of providing formal care to a broader home care population is "very sensitive" to both the functional disabilities of clients and the amount of informal care provided. (24)

Another study done by the National Center for Health Services Research suggests that some home delivered services provided only minimal benefit for the person in need of long term care. This study cautions that "before we commit ourselves to broad coverage of alternatives we should be sure that this new source of competition (home-based services) for scarce resources for the elderly needy is not going to be wasted." (25)

The Committee believes that home health and other home care services should be viable alternatives when appropriate. They suggest close examination of the current projects with respect to home care delivery for guidance in planning how to coordinate and deliver skilled nursing and intermediate care, both in and out of institutions, in the most effective way.

H. Human Resources

There is a need to recruit, train, and educate professional and non-professional long term care personnel at all levels.

Expansion of institutional and community long term care services has brought about a demand for professional and non-professional workers at all levels. The vast majority (ninety percent) -- are aides or "hands-on" employees. They provide direct services, often in unpleasant surroundings and receive minimal wages for labor that is physically and emotionally draining. The nursing home industry and community health and social service organizations estimate the need for an additional 380,000 aides and 75,000 professionals in order to provide efficient and good quality care.

Problems in the nursing home industry are compounded by growing discrepancies in wages and fringe benefits between nursing homes and hospitals. Another major problem is the increasing demand for aides in the provision of in-home services, indicating growing recruitment problems for providers of community homemaker-home health aide services.

Strategies are needed to expand career opportunities for currently employed workers combined with inducements to restructure entry positions to attract upwardly mobile individuals and volunteers -- particularly older volunteers. Possibilities are:

1. Flexible in-service training programs creating opportunities for aides to move horizontally by expanding their health and social care-giving skills. Minimally, this avoids boredom induced by routine work.

2. Development of a volunteer-employee team approach to care-giving, using case management and other techniques which stress collaborative skills related to the personal needs of the individual at risk.

Expansion of long term care community service opportunities will require that technical schools and colleges assure an adequate supply of community and social service and health specialists, such as geriatric nurse practitioners, physician assistants, and social workers with sub-specialities.

APPENDIX

FOOTNOTES

1. Health Care Financing Trends, Fall, 1980, Vol. II, No. 1, p. 2. Office of Research, Demonstration, and Statistics, Health Care Financing Administration, Baltimore, Md.

2. Karen M. Young, Program Analyst, Health Care Financing Adminstration, Office of Research, Demonstration, and Statistics, Division of National Cost Estimates, Washington, D.C.

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5. The Need for Long Term Care: Information and Issues, A chartbook of the Federal Council on the Aging, Department of Health and Human Services, Publication, Washington, D.C. February, 1981.

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7. The Well-Being of Older People in Cleveland, Ohio.

8. Estimate by the Department of Research, National Council on the Aging, 1981.

9. Future Directions for Aging Policy: A Human Services Model, p.76.

10. For estimates of the volume of long term care services provided in 1977, see: Delivery of Services to Persons with Long Term Care Needs, pp. 18-19.

11. A national program using HUD Section 8 housing subsidies to meet the housing needs of the long term care population has been proposed.

    See: Federal Policy Directions in Long Term Care, Judith Meltzer and Frank Farrow, University of Chicago, Center for the Study of Welfare Policy, May 31, 1980. P. 47.

12. Entering a Nursing Home: Costly Implications for Medicaid and the Elderly, pp. 73-77.

13. For a discussion of variability in eligibility criteria within just one program, Title XX, see Callahan, p. 20 (footnote No. 10). For a similar discussion of the Medicaid program, see the GAO Report to Congress, Entering a Nursing Home, November 26, 1979, pp. 29-38.

14. Callahan makes some of these same points in his discussion, Delivery of Services to Persons with Long Term Care Needs, p. 14.

15. Callahan discusses at length the pros and cons of single agency models in Single Agency Option for Long Term Care, pp. 99-114. See also Major Reforms in Long Term Care: A Systematic Comparison of the Options, S. S. Wallach and J. J. Callahan Jr., Brandeis University Center for Health Policy Analysis and Research, 1980, and Federal Policy Directions in Long Term Care.

16. Entering a Nursing Home: Costly Implications for Medicaid and the Elderly, pp. 123-125.

17. Mental Health and the Elderly, by Gene D. Cohen, unpublished issues paper, National Institute of Mental Health, Center for Studies of the Mental Health of the Aging, Rockville, Md. February, 1977, p. 8.

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GLOSSARY OF TERMS

1. Long Term Care: The person in need of long term care is one who, because of a social, physical and/or mental condition, is unable to cope with the tasks of daily living without assistance for an extended period of time.

   At the heart of long term care is the assumption of continuing responsibility to work in a collaborative way with the person who has a debilitating social, physical and/or mental condition and to see to the provision of items and services needed to achieve and maintain maximum freedom and activity.

   The Long term care system is the structure in which the responsibility for the person is located. An organized system of long term care should facilitate the arrangement of a variety of formal and informal services to assist the person as well as the family to achieve and maintain optimum well being.

2. Mediating Structures: A group whose members come together to meet common needs and, in so doing, develop a sense of identity as well as mutual supports.

   The first and most perfect expression of the capacity and need of human beings for such belonging is the family, but is also found in neighborhoods and a variety of voluntary associations (such as labor unions, service clubs, and community organizations), churches and synagogues. Through such mediating structures people share burdens and joys through a variety of experiences. They have meaning at all stages of life but particularly at time of need.

3. Case Management: As used in this paper, case management is that process through which assessment takes place, program eligibility is determined, service linkages are established, and the vulnerable person, and his/her informal supports, are assisted in meeting the challenges of every day living.

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Research in Aging

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the 1981 White House Conference on Aging

Executive Summary of Technical Committee on SOCIAL & HEALTH ASPECTS OF LONG TERM CARE

TCES-8

NOTE: The recommendations of this document are not recommendations of the 1981 White House Conference on Aging, or the Department of Health and Human Services. This document was prepared for the consideration of the Conference delegates. The delegates will develop their recommendations through the processes of their national meeting in late 1981.

TECHNICAL COMMITTEE MEMBERS

MSGR Charles J. Fahey, S.J., Director
Center on Gerontology, Fordham University, NY
Chairman, Federal Council on Aging

Joseph E. Becker
Nursing Home Administrator
Masonic Home, NJ

John Beck, MD, Director
Division of Geriatric Medicine
UCLA

Homer W. Cunningham, President & Chairman of the Board
Progressive Medical Groups, Inc.
VA
Chairman of the Board, Meals on Wheels, VA

William L. Gee, DDS, President
On-Lqk Senior Health Services for Pacific/Asians, CA

Ernesto Martinez, Director of Senior Programs
East Harlem Council for Human Services, NY

Joan Quinn, MS, RN, Executive Director
TRIAGE Long-Term Care Project, CT

William Reichel, MD, President
American Geriatrics Society
Washington, DC

Janet S. Sainer, MS
Commissioner, NYC Department for the Aging, NY

Malcolm O. Scamahorn, MD
Chairman, Committee on Aged and Long-Term Care
American Medical Association, IL

Jerry D. Smart, President
American Association of Homes for the Aged, DC

Herbert H. Shore, Ed.D.
Executive Vice President
Dallas Home for Jewish Aged, TX

Gladys R. Voegtli, Chairman
Long-Term Planning Committee
State Advisory Council to the Wisconsin Bureau on Aging

Ellen Winston, Ph.D., Chairman
N.C. Governor's Advisory Council on Aging
President, National Council on Aging
Deputy Chairman, 1981 White House Conference on Aging

COMMITTEE STAFF, CONSULTANTS, EXPERTS

Charles Culhane
Consultant-Writer
Washington, DC

Burton Dunlop, Ph.D.
Abt Associates
Washington, DC

Elizabeth D. Flynn
White House Conference on Aging Staff

Douglas S. Hill
White House Conference on Aging Staff

I. INTRODUCTION

The most commonly held perception of long term care is one of institutional services. In fact, long term care involves not only institutional services, but a wide range of social as well as health services provided to people in a variety of settings.

The 1971 White House Conference on Aging expressed the need for an organized system of long term care. The 1981 White House Conference on Aging Long Term Care Technical Committee has focused on what continues to be a "non-system" of long term care, by recommending that public policymakers fashion and demand an organized and coordinated delivery system of long term care that is fully cognizant of both social and health needs. The person in need of long term care is one who, because of a social, physical, and/or mental condition, is unable to cope with the task of daily living without assistance for an extended period of time. It is the belief of the Committee that such a person be the focus of a long term care system.

Nursing home expenditures during the twelve months ending in June 1980, were 19.3 billion dollars. (1) Based on the most recent available data, non-institutional health and social services expenditures provided under the Older Americans Act and the Social Security Act were approximately 1.3 billion dollars.* (2)

Based on these striking facts and on the widespread dissatisfaction with the current approach, the committee has determined a need for a coordinated approach to long term care and support in which the institutional and non-institutional components may be more appropriately balanced. There should be a continuum of social and health support services, both institutional and non-institutional which allow for home-based and/or community care, encouraging maximum functional independence.

Long term care financing has focused primarily on care provided in medical institutions. As a result, the system has been driven in that direction by policies that foster institutionalization. Few options are available to older persons who need social or medical services that will assist them to remain in their homes or other residential settings.

Demographic projections consistently show a substantial increase in the number of older persons in the United States over the next thirty years. As this population increases, so will the number of older adults who will require care and support. Presently, approximately eighty percent of the care and support available to older adults is provided by family members or other informal support systems. It is essential that any formal long term care system recognize and support the informal system presently at work. Further, such a system should help to facilitate the provision of a variety of formal and informal services to assist older people to achieve and maintain optimum well-being.

The Committee, during the course of its work, identified the following assumptions and values which were important factors in its recommendations. They do not constitute a definitive list, but highlight some of the more important background elements for consideration by White House Conference delegates.

II. ASSUMPTIONS

1. Most long term care is provided within the context of the family and other informal supports. In some instances formal supports supplement and even make such care possible.

2. The demand for long term care will grow as more Americans continue to live to advanced ages.

3. Financial contraints will intensify:

   a. Other national priorities will compete with and restrain the growth of publicly financed health and social services;

   b. Inflation will probably persist in the health and social service fields.

4. Functional disability occurs at all ages but particularly among older Americans.

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* Due to the fact that the state of data collection in long term care is neither ordered nor unified, truly equivalent comparative data are not available. This particular comparison is based on two sets of data;

1. Quartely annual costs of social services under Title XX- of the Social Security Act; October 1978-September, 1979.

2. Quarterly Financial Status Report, Title III-B and III-C of the Older Americans Act; 9-30-80; 6-30-80; 3-31-80; 12-31-79.

5. The nature of disability is such that functional changes are likely to occur. Programs must be flexible in order to be responsive to an individual's changing level of needs.

III. VALUES

1. Society should assure that humane continuing care is provided to vulnerable individuals in their own homes where possible or in group settings when necessary.

2. Long term care services should be available to persons with functional limitations who need assistance.

3. Society should ensure that necessary services, both formal and informal, are available.

4. The system should provide services to people at home and in institutions.

5. Programs should be flexible to respond to individuals' changing needs.

6. Government should provide a variety of services that assist families and other mediating structures with informal care giving.

7. The individual should be able to choose among service options.

8. Cultural, religious, and ethnic preferences should be respected in the provision of service.

9. Care that is provided should foster independence.

10. Government should assure that the rights and dignity of all persons, including those who are most vulnerable and most in need of services, are preserved.

IV. MAJOR FINDINGS

Some of the Committee's major findings are the following:

1. The focus of a long term care system is the person who has functional difficulties and is in need of assistance in the activities of daily living in order to assure continuing independence.

2. Public policy should provide for the enhancement and supplementation of the individual, of the family, of significant others, and other mediating structures.

3. Each community should have a publicly sanctioned long term care system which provides for services that would insure continuity of care, multiple entry points, and coordination of needed social and health services in in-home and institutional settings through governmental, proprietary, and non-profit organizations.

4. A Long term care Assessment/Case Management* function should be available to all persons seventy-five and older, as well as to those who are functionally disabled under age seventy-five as a matter of entitlement.

V. KEY ISSUES

1. How should public policy enhance the care giving capacity of family and friends as part of the informal system of long term care?

2. Should there be a local system of long term care and what should be its characteristics?

3. Should all functionally disabled persons be eligible for a case assessment and case managment system as a matter of entitlement?

4. What can be done to assure a balance between institutional and non-institutional services? e.g. How should services in in-home and institutions be provided in the least restrictive environment appropriate to an individual's functional capacity?

5. How can the current reimbursement system for health care providers be improved?

6. How should appropriate and quality care for dependent persons be assured?

7. Should the federal government study the feasibility of a social service insurance program for disabled persons?

VI. RECOMMENDATIONS

The Committee's recommendations on long term health care are the following:

* See Glossary

1. The Focus: The focus of a long term care system is the person who has functional disabilities and is in need of assistance in the activities of daily living in order to assure continuing independence.

2. Informal Supports: Public policy should enhance and supplement the capability of the individual, of the family, significant others, and other mediating structures. Assistance may take the form of financial help, such as income supplements and/or tax incentives, and social supports, such as day care and respite services.

3. The System: Each Community should have a publicly sanctioned long term care system which provides for:

   a. A person-focused case management system with the capacity to assess need, determine eligibility, provide links for those in need of formal services, and assists the person in his or her informal support system;

   b. Continuity of care, that assists informal supports, provides multiple entry points, makes available both in-home and group services, offers both social and health services, provides psycho-social and health assessments and re-assessments, makes resources available in order to fill gaps in service;

   c. Sufficient data capacity to facilitate planning;

   d. Appropriate control over reimbursement to providers;

4. Mental Health: Mental health should be an integral part of a comprehensive long term care health and social service delivery system. Funding patterns should reflect such integration.

5. Sponsorship:

   a. Public policy should recognize pluralism in sponsorship. Private investment, governmental, and philanthropic non-profit agency efforts are all necessary.

   b. Medicaid reimbursement should cover the actual cost of necessarily incurred servcies.

6. Quality and Appropriateness Assurance

   a. There is a need to define as well as refine techniques for guaranteeing quality and appropriateness of care.

   b. Quality and appropriateness assurance should assume the basic integrity of providers. Sanctions should be applied promptly and fairly when abuse occurs.

c. Community presence and involvement, provided by volunteers, friends, and neighbors, are important elements in helping to ensure quality care and should be encouraged.

7. Financing the System:

a. Medicare, Medicaid, Title XX, and programs authorized by the Older Americans Act, as well as other major social service programs that address the various aspects of long term care needs, should be maintained and strengthened.

b. The basic functions of the long term care system, i.e., client assessment, eligibility determination, and case management, should be made available, as a matter of entitlement, to all persons over 75 as well as those who are functionally disabled under 75.

c. Federal funding should be available for emergency community and individual services to fill gaps identified through the client assessment and case management process.

d. An immediate study should be made of the feasibility of funding a social insurance program for long term care.

e. The current level of living of the spouse of a person in need of long term care should not be lowered by requirements that force the non-institutionalized person to contribute excessive amounts of money to pay the costs of care for his or her disabled spouse.

f. A federal housing strategy should be developed which provides social supports to maintain an individual independently while helping to avoid premature or unnecessary institutionalization.

g. Persons who are otherwise eligible for Medicaid, that need skilled or intermediate in-patient care, should be eligible for equivalent in-home services so long as the in-home expenditure does not exceed comparable in-patient cost. State Medicaid plans should reflect such a policy.

8. Manpower: There is a need to recruit, train, and educate professional and non-professional long term care service personnel at all levels.

VII. GLOSSARY OF TERMS

1. Long Term Care: The person in need of long term care is one who, because of a physical and/or mental condition, is unable to cope with the tasks of daily living without assistance for an extended period of time.

   At the heart of long term care is the assumption of continuing responsibility to work in a collaborative way with the person who has a debilitating physical and/or mental condition and to see to the provision of such items and servcies needed to achieve and maintain freedom and activity.

   The long term care system is the structure in which the responsibility for the person is located. An organized system of long term care should facilitate the arrangement of a variety of formal and informal services to assist the person as well as the family to achieve and maintain optimum well being.

2. Mediating Structures: A group whose members come together to meet common needs and in so doing develop a sense of identity as well as mutual supports.

   The first and most perfect expression of the capacity and need of human beings for such belonging is the family, but is also found in neighborhoods and a variety of voluntary associations (such as labor unions, service clubs and community organizations) churches and synagogues.

   Through such mediating structures people share burdens and joys through a variety of experiences. They have meaning at all stages of life but particularly at time of need.

3. Case Management: As used in this paper, case management is that process through which assessement takes place, program eligibility determined, service linkages established and the vulnerable person and his/her informal supports are assisted in meeting the challenges of every day living.

NOTES

1. Health Care Financing Trends, Fall 1980, Vol. II #1 p.2 Office of Research, Demonstration and Statistics Publication, Health Care Financing Administration, Baltimore, Maryland.

2. Karen M. Young, Program Analyst, Health Care Financing Administration: Office of Research, Demonstration, and Statistics; Division of National Cost Estimates, Washington, D.C.

The following Technical Committee Summaries have been published:

Retirement Income
Health Maintenance and Health Promotion
Health Services
Social and Health Aspects of Long Term Care
Family, Social Services and Other Support Systems
The Physical and Social Environment and Quality of Life
Older Americans as A Growing National Resource
Employment
Creating an Age Integrated Society: Implications for Societal Institutions
Creating an Age Integrated Society: Implications for the Economy
Creating an Age Integrated Society: Implications for the Educational Systems
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